

**Leah Eskenazi, Manager, Senior; Community Programs  
Legacy Health System - Portland, Oregon**

**Presentation Summary- Local Perspective**

Most people want to follow through on the stated or unstated promise to care for a loved one, but are not prepared to do so. This often leads to a sense of guilt, anger and self doubt. A desire to educate and build confidence in family and friend caregivers led to the development of Legacy Health System's Caregiver Services in Portland Oregon 17 years ago. At that time Legacy offered an 8 week education series on managing chronic illness and 500 people attended the first night! A survey of 200 caregivers the following year conducted by the local Area Agency on Aging indicated that the top need of caregivers was, "to just have a break now and then". Our Respite program was initiated later that year.

**Greatest Strengths of local efforts:**

**1 - Collaboration** - Oregon is strongly committed to community based care which fosters local collaboration. Legacy is currently collaborating on projects with the local Alzheimer's Association, state and local senior services divisions, the Oregon Health Sciences University, Trinity Episcopal Cathedral, other health systems and community based organizations.

**2 - Healthcare Sponsorship** - Long term sponsorship by a respected community hospital with a family resource center and on site experts provides program credibility and promotes caregiver trust. Legacy is the most comprehensive and best know caregiver resource in Oregon. Operating in a managed healthcare environment gives us direct knowledge and opportunities to reduce the burdens faced by individuals with chronic illness and their caregivers.

**3 - Low regulation environment** - The current flexibility of federal, state or local regulations has allowed high quality, low cost, innovative respite and caregiver programs to flourish. For example Legacy's Alzheimer's group respite programs are staffed in part by people experienced in the arts and family caregiving. More expensive healthcare personnel are only used when their level of skill is truly needed, saving consumers countless dollars.

**Greatest challenges:**

**1 - Families wait too long to seek help.** In too many cases, it seems that caregivers die sooner than the people for whom they have cared. Caregivers often delay attending to their own health and well being. Society needs to do a better job of promoting caregiving as a cultural value and the use of organized public and private sector services (formal system) to support family and friends (informal system) who care.

**2 - Financial** - Few incentives or resources are available to help families pay for services, sustain existing public and private sector programs or to encourage increased healthcare participation in this social model of care.

**3 - Communication between healthcare professionals and caregivers is inadequate.** Increasing emphasis on controlling healthcare utilization and cost of care puts a premium on the time spent by health care providers with their patients. Patients are increasingly expected to direct their own care. The challenge is to empower both caregiver and healthcare professional to be more intelligent about caregiving, thus enabling them to bridge the current communication gap.

## **Legacy Caregiver Services - Core Services**

**Legacy Caregiver Services** is a social services program located in a hospital, that is part of Legacy Health System. Based in Portland, the system consists of four hospital and a VNA. The sole mission of our department is to serve caregivers. The philosophy of Legacy Caregiver Services is embedded in its motto, "You're Not Alone". Our programs are designed as a partnership with caregivers and links the informal and formal systems of care. (See: Family Support Model diagram). The individual is in the center supported by family and friends. With chronic illness the medical care system and other formal services must work with the patient support network to provide optimal support for the individual and family. Legacy's family support model seeks to bridge the informal network and formal systems of care by helping to build competency and self reliance in families and patients, and eliminate barriers to care within the medical care system and others.

The core programs include:

**Information and referral** - The center has a large collection of information about health problems and caregiving, including 1300 books and video tapes, in addition to pamphlets, newsletters and internet access to health information and disease management resources. The center and Respite service receive over 2000 calls/walk-in's a month.

**Education and support** - Community education programs are offered regularly including the Caregiver Series, Understanding Medicare, Legacy/financial issues, strategies for Alzheimer's, stroke and head injury care classes. Access to a wide range of support networks are available through the Center including the Center's coordination of 25 support groups.

**Respite services** - Over 20,000 hours of respite care are provided to families through an In-Home service and at two Brookdale model group respite programs, Trinity Place and St. Aidan's Place. Professional caregiver training classes are offered bi-monthly and a listing of 50-60 private duty caregivers is updated and distribute monthly throughout the community with a hiring guide.

**Both quantitative and qualitative data** is used to drive program development activities.

Legacy is fortunate to have a Caregiver Researcher on staff, Dr. Linda Boise, who ensures that we are up to date on the needs of caregivers in our community. The staff makes every effort to translate relevant research findings into policy and practice. In addition, Legacy's strong emphasis on Continuous Quality Improvement provides us with a supportive environment to use customer satisfaction and program effectiveness data for decision making.

**Four key Legacy projects:**

**1) By helping families help themselves, the majority of families can best manage their own needs. This core belief led Legacy to develop a 3-year project called the "Caregiver Self-efficacy Education Project".**

- A six week caregiver training class with education book.
- Based on Lorig's (Stanford Univ,) self-efficacy model for chronic care.
- Currently being tested Alzheimer's, stroke, Parkinson's disease caregivers in a train-the-trainer model.
- Pilot test classes and Nine six-week classes completed in Portland area. Nine more classes scheduled to start in October. Comparative data from classes will be analyzed with results

prepared by winter.

- A class leader guide and caregiver help book are being prepared for publication.
- We are seeking grant support for regional and/or national dissemination.

One of the pilot class participant, whose husband has Alzheimer's disease, said:

"This was a different kind of program. The focus was on Caregivers [not caregiving tasks]. They didn't let us cry for very long about our problems, but showed us how to cope with our problems, communication with our Receivers, let go of guilt feelings of inadequacy in our caregiving, ... how to recognize signs of depression in ourselves and seek help, reduce stress and problem solve... "

**2) The second key initiative is "Building Caregiver Bridges in a Managed Care World"** - This grant supported project builds on current and developing caregiver services activities to enhance the ability of family caregivers to work with health providers, including physician. One component, supported by a National Alzheimer's Association grant, involved investigating the process of clinical assessment and diagnosis for dementia and to identify barriers to proper diagnosis.

- Eighteen focus groups with 78 Primary Care physicians were conducted in Portland, rural Oregon and Cleveland, Ohio.
- MD's clearly understood Alzheimer's clinical assessment tools and strategies.
- A reluctance to give a diagnosis of Alzheimer's disease was reported for a variety of reasons, including MD perception that since they could not make a difference there was no benefit to making the diagnosis.

"I think the thing that the diagnosis is really about is helping to prepare the family and the patient with that transition from when the patient isn't always able to care for themselves and the family isn't able to - and the transition to the family not being able to do it. At least we get the family prepared, so if they want to do it, they get the resources so we don't have the situation where you have family bringing in dad or grandpa to the ER, 'I can't take care of my dad anymore,' and they're gone."

- Findings from this study are being disseminated locally and nationally.

**3) A third initiative: Training 4th year medical students.**

- Collaborative project with Alzheimer's Association and medical school.
- Students learn about Alzheimer's disease and community resources through on-site participation at St. Aidan's Place Assisted Living, Trinity Place and St. Aidan's Place Group Day Respite programs and at the Alzheimer's Association.
- Required as part of Neurology clerkship rotation.
- Active, positive engagement of individuals with dementia at programs and discussion about community resources is effective in broadening student perception about dementia care options.
- "There is nothing I can do" attitude is addressed and dispelled.
- Project is beginning it's second year of monthly training sessions.

**4) A Forth initiative uses visual arts to educate and show the continuing contribution of people suffering from a dementing illness.**

- Kaleidoscope: An Exhibit Celebrating the Creativity of Individuals with Alzheimer's Disease is a beautiful 23 piece intergenerational art exhibit showcasing the creative talents of people with Alzheimer's disease.

- Created at Trinity Place with the help of local artists, the exhibit was expanded to include work from three other states and is travelling nationally, thanks to a grant from the Brookdale Foundation.
- It is an uplifting, professional exhibit. It helps to raise the self esteem of both Alzheimer's caregivers and care receivers. The exhibit also educates people about Alzheimer's disease from a strengths perspective.

**You are welcome** to contact me if you are interested in more information about any of Legacy's services or projects. (503)413-6778 or [leskenaz@lhs.org](mailto:leskenaz@lhs.org)